A Study Prepared

By the Alzheimer's Association

For the Governor's Task Force on Alzheimer's Disease and Related Senile Dementias

As directed by the Indiana Legislative Council

Pursuant to Senate Concurrent Resolution 18

June 30, 2002

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Executive Summary

In 2002, the Indiana Alzheimer's Association convened a Working Group of consumers, long- term care professionals, and state agencies to complete a study of aggressive and potentially harmful behavior among long-term care residents pursuant to Senate Concurrent Resolution 18. A summary of findings presented by the Group to the Governor's Task Force on Alzheimer's Disease and Related Senile Dementia follows:

Data is limited on the incidence and degree of harm caused by resident aggression. Indiana may wish to participate in more detailed studies if they are undertaken and funded by the federal government or private sources.

While the Working Group initially focused on aggressive behavior *among nursing home residents toward other residents* – as charged – it found in literature and practice at least equal *concern about aggressive behavior of residents toward staff and family members in a variety of settings including home care, assisted living, adult day care, and so on*. The problem of aggressive behavior concerns not only family members of victims, but also family members caring for aggressive loved ones, direct care staff, and administrators subject to liability and occupational health and safety (OSHA) issues.

Moreover, while the Working Group initially focused on aggressive behavior among nursing home residents *with Alzheimer's disease and other forms of dementia* -- as charged -- it eventually recognized that aggressive behavior is a problem among a *larger pool of nursing home residents, including residents with mental illness, co-occurring mental illness and dementia, physical health problems such as urinary tract infections, pain, and a history of violent or criminal behavior*. Indeed the aggressive Evansville nursing home resident that prompted this study had a violent criminal history as well as alcohol-related dementia.

Consequently when estimating the scope of the problem, the Working Group included information on behaviors as well as diagnoses of dementia. *Demographic trends* imply that these problems will grow over time as the Indiana population ages. Dementia is more prevalent with age.

The Indiana State Department of Health (ISDH) conducts annual surveys of the 600+ Indiana long-term care facilities and investigates complaints from the public. ISDH reports that:

- During the most recent six-month period (12-1-01 to 5-16-02) ISDH received 11 complaints *from the public* of resident-to-resident abuse; if annualized this would equal about 22 complaints of resident-to-resident abuse per year.
- During the same six-month period *long-term care facilities reported* to ISDH 571 incidents of resident-to-resident abuse (of about 5,000 incidents reported by long term care facilities); if annualized this would equal about 1,142 incidents (of about 10,000 incidents reported by facilities per year).

The Office of Medicaid Policy and Planning (OMPP) provided very useful data from the Minimum Data Set (MDS), an assessment tool use by long-term care facilities pursuant to federal guidelines. It shows that aggressive behavior is an important problem but it is not widespread. While 29% of the nursing home population displayed one or more behavioral symptoms (wandering, verbal abuse, physical abuse, inappropriate/disruptive behavior, or resisting care), only 5% (n=2,134) displayed physically aggressive behavior and a lesser proportion displayed physically abusive behavior that was difficult to change

(3%)(n=1,276). Studies in other states indicate that an even smaller portion actually cause harm to others.

MDS data indicate that only a portion of physically aggressive residents are cognitively impaired (60-94% depending on the degree of cognitive impairment counted) and only a portion of these have Alzheimer's disease.

Studies indicate that aggressive behavior is associated with a variety of factors, including but not limited to dementia:

Factors related to **residents include:**

- Previous history of violence/criminal record
- Untreated pain or other discomfort
- Medical conditions, such as urinary tract infections
- Depression, other mental illness, co-occurring disorders
- Males
- Mid to late stage Alzheimer's disease
- Other forms of dementia not related to Alzheimer's, such as head injury and alcoholism (younger and stronger residents with other dementias sometimes are placed in special care units for behavior management)
- Provocation by other residents and caregivers, often during assistance with Activities of Daily Living (ADLs)

Factors related to **facilities and the overall delivery system include:**

- Insufficient training on dementia and behavior management for professionals caring for geriatric population (physicians, nurses, aides, etc); insufficient use of behavior management techniques (environmental changes, acceptance)
- Inadequate use and training in proper use of medications
- Inadequate supply of caregivers specially trained in geriatrics, ranging from aides to nurses to social workers to physicians; not enough staff
- Beyond dementia, large numbers of nursing home residents with mental health needs contributing to aggressive behavior
- Insufficient early assessment and treatment of behavioral and mental health conditions, especially for residents excluded from pre admission screening & resident review (PASRR) due to the federal dementia exclusion
- Lack of awareness of reimbursement options available in Indiana for mental health services
- Shortage of geriatric mental health professionals in nursing homes, in private practice, and in community mental health centers
- Lack of highly specialized "Facilities of Last Resort" for treating behavioral disorders
- Limitations in reimbursement and regulation of dementia care in special care units
- Limitations in criminal justice and adult protective service systems

Although several states have implemented models that could be considered in Indiana, generally resident aggression has not been studied in depth or addressed systematically throughout the U.S. National advisors indicated that Indiana may be in the forefront in tackling this issue.

Many of the factors contributing to aggressive behavior can be addressed in order to prevent and minimize aggression. The Indiana Working Group **recommends strategies** including the following:

- Make greater use of behavior management techniques to minimize the majority of behavioral symptoms, including physical aggression
- Provide more training for caregivers (ranging from aides to physicians) in use of behavior management techniques
- Provide more training in proper treatment protocols including drug treatment
- Ensure that appropriate medications/protocols are included on the preferred drug list under development by the Drug Utilization Review Board
- Increase the supply of health professionals with geriatric training, including aides, LPNs, RNs, nurse practitioners, advanced practice nurses, social workers, mental health practitioners, and physicians.
- Refer human resource needs to the Governor's Commission on Caregivers for the Continuum, a group already working on human resource issues.
- Ensure early assessment and treatment of mental health conditions, notably co-occurring dementia and depression; help facilities locate mental health providers.
- Educate families and providers about the availability of Medicaid, Medicare and other reimbursement for delivering mental health services to long term care residents
- Expand the pool of mental health professionals, especially those cross trained to provide geriatric services
- Encourage community mental health centers to provide geriatric services; market centers that currently offer such services
- Bring care on site rather than move or transfer patients
- Involve regulators, such as the Indiana State Department of Health, in collaborating on solutions, with ongoing training on dementia, behavior management, documentation needs, treatment/drug protocols, mental health screening, etc.
- Create several highly specialized nursing "facilities of last resort" to treat the most difficult behaviors (less than 1,000 people) and to provide technical assistance to other care providers.
- Consider findings from a previous FSSA study acknowledging the need for additional reimbursement of special care units under certain conditions; consider a similar study for all residents with behavior symptoms, with and without dementia.
- Consider other criminal justice and adult protective services system changes to address violent behavior among elderly persons supervised and not supervised by the courts.

Introduction

In 1999 a highly publicized Evansville case of deadly assault by one nursing home resident against another galvanized interest in the subject of aggressive behavior within nursing homes. The victim's family pursued corrective action and sued the nursing home. (**See Appendix 1 for an article about this case.)** At the urging of the victim's family along with a coalition of interest groups, Senator Greg Server initiated a legislative response to this issue, resulting in passage of Senate Concurrent Resolution 18 (SCR 18) during the 111th Regular Session of the Indiana General Assembly (2000). **A copy of SCR 18 is included as Appendix 2.**

SCR 18 calls for an interim study of the *issues relating to the availability of care for individuals suffering from the effects of dementia or related diseases*. Specifically SCR 18 provides that the *study committee, if established, shall study and may make recommendations concerning the following issues:*

- *Define the full scope and severity of the problems resulting from the lack of adult care programs and facilities providing a higher level of service to meet the increased needs of individuals prone to violent behavior due to the effects of dementia and related diseases.*
- *Identify factors contributing to the above-identified problems.*
- *Identify alternative types of care being utilized in other communities to address the above-identified problems.*
- *Recommend action to ameliorate the above-identified problems and provide for the improved health and safety of individuals suffering from the effects of dementia or related diseases, for other residents with whom they live, and for the staff charged with caring for such individuals.*

The Indiana Legislative Council assigned responsibility for the SCR 18 study to the Governor's Task Force on Alzheimer's Disease and Related Senile Dementia, which contracted with the Indiana Chapter of the Alzheimer's Association for technical assistance. To complete its research, the Alzheimer's Association formed a Working Group consisting of the following members:

Working Group Member	**Representing: Government Agencies:**
Louann Lawson	Governor's Task Force (Chair)
Drew Klatte	Indiana Division of Mental Health and Addiction
Liz Carroll	Indiana State Department of Health
Arlene Franklin	FSSA Bureau of Aging and In Home Services
Working Group Member	**Representing: Consumers:**
Robyn Grant	Alzheimer's Association Public Policy Committee

Caryl Hancock	Family Member of a Victim
Judy Dockery	Long Term Care Ombudsmen (Evansville)
Kevin Kilty	Mental Health Association in Indiana

Working Group Member	**Representing: Nursing Home Profession:**
John Niemeyer	Indiana Health Care Association (IHCA)
Jim Leich	Indiana Association of Homes & Services for the Aging (IAHSA)
Bob Decker	Hoosier Owners & Providers for the Elderly (HOPE)

Working Group Member	**Representing: Staff/Technical Assistance:**
Heather Hershberger	Alzheimer's Association
Michael Sullivan	Alzheimer's Association
Carol Kramer	Kramer & Company

The Working Group held a series of information-gathering meetings on the following dates with the following speakers and topics:

Date in 2002	**Speakers/Topics**
February 25	Organizational meeting
April 22	Dr. Patrick Healey, St. Vincent Hospital Institute on Aging: Medical Parameters and Treatment of Dementia Becky Koors, Indiana Bureau of Aging and In Home Services: Pre Admission Screening and Resident Review
May 6	Willard Mays, Division of Mental Health and Addiction: Mental Health and Aging
May 20	Sue Hornstein, Indiana State Department of Health: Nursing Home Data and Regulatory Parameters Lee Strawhun, Southlake Mental Health Center: Pilot Behavior Management/Mental Heath Nursing Home
June 3	Evelyn Murphy, FSSA Office of Medicaid Policy and Planning and Myers & Stauffer Team: MDS Data & Reimbursement of Special Care Units Jim Leich, John Neimeyer, and Bob Decker: Reimbursement Issues & Nursing Home Perspective

	Preliminary discussion of findings & recommendations
June 24	Discussion of draft report findings and recommendations

The Working Group also interviewed and collected data through resource persons/groups including the following:

Resource People	**Representing:**
Judy Miller, Judy Riggs, Katie Maslow	National Alzheimer's Association Public Policy Division
Dr. Constantine Lyketsos	Johns Hopkins Department of Psychiatry Institute of Medicine Study of Elder Abuse
Focus group conducted on 4/10/02 and summarized in **Appendix 3.**	Indiana Long Term Care Ombudsmen from 16 areas throughout Indiana

The National Alzheimer's Association Public Policy Division completed a literature search for articles on aggressive behavior. The Alzheimer's Association, National LTC Ombudsman Resource Center, and Indiana Association of Homes and Services for the Aging queried their counterparts to seek information on best practices in other states. Project staff/technical assistants completed a literature review of articles and books recommended by working group members and resource people. The following report summarizes their work.

1. Scope/Severity of the Problem(s)

SCR 18: Define the full scope and severity of the problems resulting from the lack of adult care programs and facilities providing a higher level of service to meet the increased needs of individuals prone to violent behavior due to the effects of dementia and related diseases.

Statistics on Incidence of the Problem in Indiana

While the Working Group initially focused on aggressive behavior *among nursing home residents toward other residents* – as charged – it found in literature and practice at least equal *concern about aggressive behavior of residents toward staff and family members in a variety of settings including home care, assisted living, adult day care, and so on*. The problem of aggressive behavior concerns not only family members of victims, but also family members caring for aggressive loved ones, direct care staff, and administrators subject to liability and occupational health and safety (OSHA) issues.

Moreover, while the Working Group initially focused on aggressive behavior among nursing home residents *with Alzheimer's disease and other forms of dementia* -- as charged -- it eventually recognized that aggressive behavior is a problem among a *larger*

pool of nursing home residents, including residents with mental illness, co-occurring mental illness and dementia, physical health problems such as urinary tract infections, pain, and a history of violent or criminal behavior. Indeed the aggressive Evansville nursing home resident that prompted this study had a violent criminal history as well as alcohol-related dementia.

Consequently when estimating the scope of the problem, the Working Group included information on behaviors as well as diagnoses of dementia. *Demographic trends* imply that these problems will grow over time as the Indiana population ages. Dementia is more prevalent with age.

Data from Indiana Office of Medicaid Policy and Planning

*Given the variety of conditions associated with aggression, the Working Group concluded that one of the most useful data sources for estimating the scope of the problem is the **Minimum Data Set (MDS)** an assessment tool collected uniformly from nursing facilities throughout the United States as required by the Center for Medicare and Medicaid Services (CMS, formerly HCFA).* The **Indiana Family and Social Services Administration (FSSA) Office of Medicaid Policy and Planning (OMPP),** along with its contractor Myers & Stauffer, used Indiana MDS data to report to the Working Group on behavior patterns among nursing facility residents.

MDS data is collected/reported by nursing homes for all residents upon admission and quarterly thereafter (more often if there is a change of resident condition). It provides a "snapshot" view of nursing home residents *at a one-week point in time*. Five types of behavioral symptoms are tracked by the MDS:

- **Wandering** – Moved with no rational purpose, seemingly oblivious to needs or safety.
- **Verbally Abusive Behavioral Symptoms** – Others were threatened, screamed at, cursed at.
- **Physically Abusive Behavioral Symptoms** – Others were hit, shoved scratched, sexually abused.
- **Socially Inappropriate/Disruptive Behavioral Symptoms** – Made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behavior or disrobing in public, smeared/threw food/feces, hoarding, rummaged through others' belongings.
- **Resists Care** – Resisted taking medications/injections, ADL assistance, or eating.

The following tables summarize the number and percent of Indiana nursing home residents exhibiting each of these five behavioral symptoms in 2001, along with the unduplicated total. Data was fairly consistent over time for the past three years. The pool of Indiana nursing home residents assessed each year was slightly over 40,000.

2001 Indiana Nursing Facility	Wandering	Verbally Abusive	Physically Abusive	Inappropriate Disruptive	Resists Care	Unduplicated Total

Mood and Behavior Patterns Based on MDS Data at a Point in Time # Assessments = 40,098 NUMBER OF RESIDENTS						
Behavioral Symptoms – Frequency						
Behavior not exhibited	36,566	36,848	37,964	35,178	33,382	28,287
Behavior exhibited	3,532	3,250	2,134	4,920	6,716	11,811
Behavior frequency:						
Occurred 1 to 3 days in last 7	1,318	2,374	1,626	2,786	4,263	Na
Occurred 4 to 6 days in last 7	603	551	300	1,026	1,268	Na
Occurred daily	1,611	325	208	1,108	1,185	Na
Behavioral Symptoms – Alterability						
Behavior not exhibited or easily altered	38,087	38,145	38,793	36,840	35,271	Na
Behavior was not easily altered	1984	1,927	1,276	3,236	4,805	Na
Behavioral Symptoms – Change in Behavioral Symptoms Compared to 90 Days Ago N = 15,970						
No change	Na	Na	Na	Na	Na	14,020
Improved	Na	Na	Na	Na	Na	767
Deteriorated	Na	Na	Na	Na	Na	1,183

Source: Indiana Office of Medicaid Policy and Planning based on 2001 MDS data

2001 Indiana Nursing Facility Mood and Behavior Patterns Based on MDS Data at a Point in Time # Assessments = 40,098 PERCENT OF RESIDENTS	**Wandering**	**Verbally Abusive**	**Physically Abusive**	**Inappropriate Disruptive**	**Resists Care**	**Unduplicated Total**

Behavioral Symptoms – Frequency						
Behavior not exhibited	91%	92%	95%	88%	83%	71%
Behavior exhibited	9%	8%	5%	12%	17%	29%
Behavior frequency:						
Occurred 1 to 3 days in last 7	3%	6%	4%	7%	11%	Na
Occurred 4 to 6 days in last 7	2%	1%	1%	3%	3%	Na
Occurred daily	4%	1%	1%	3%	3%	Na
Behavioral Symptoms – Alterability						
Behavior not exhibited or easily altered	95%	95%	97%	92%	88%	Na
Behavior was not easily altered	5%	5%	3%	8%	12%	Na
Behavioral Symptoms – Change in Behavioral Symptoms Compared to 90 Days Ago N = 15,970						
No change	Na	Na	Na	Na	Na	88%
Improved	Na	Na	Na	Na	Na	5%
Deteriorated	Na	Na	Na	Na	Na	7%

Source: Indiana Office of Medicaid Policy and Planning based on 2001 MDS data

Based upon these MDS data, at a point in time, the unduplicated total number of nursing home residents exhibiting one or more behavioral symptoms was 29% (11,811 of 40,098). The most common behavioral symptom was resisting care (12% of residents), followed by inappropriate or disruptive behavior (8% of residents). At any point in time only 5% of residents (2,134) displayed physically abusive behavior, the type of behavior most likely to cause harm to others, the type most applicable to this study.

A smaller portion exhibited behaviors were not easily altered, ranging from 3% (1,276) for physically abusive behavior to 12% (4,805) for resisting care. Most (88%) showed no change compared to 90 days ago, while 767 (5%) improved and 1,183 (7%) deteriorated.

Various studies have shown that even smaller portions of these residents actually cause harm to others, but data was not available with which to assess actual harm caused by Indiana nursing home residents.

The following table uses MDS data to depict the relationship between behavioral symptoms and cognitive impairment. Cognitive Performance Scores (CPS) range from 0-6 with 0 = intact cognition, 1 = borderline intact cognition, 2 = mild impairment of

cognition, 3 = moderate impairment, 4 = moderate to severe impairment, 5 = severe impairment, and 6 = very severe impairment.

MDS 2001 Mood & Behavioral Pattern	**Degree of Cognitive Impairment, with 0 = intact cognition and 6 = very severe impairment**							
Number:	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**Total**
Wandering	13	42	107	1,439	587	1,202	142	3,532
Verbally Abusive	145	340	184	1,438	371	605	167	3,250
Physically Abusive	21	59	52	721	317	705	259	**2,134**
Inappropriate/ Disruptive	122	370	224	1,824	638	1,095	647	4,920
Resists Care	302	610	328	2,425	816	1,434	801	6,716
Total Unduplicated	479	1,001	641	4,507	1,467	2,476	1,240	**11,811**

Source: Indiana Office of Medicaid Policy and Planning based on 2001 MDS data

MDS 2001 Mood & Behavioral Pattern	**Degree of Cognitive Impairment, with 0 = intact cognition and 6 = very severe impairment**							
Percent of 40,098:	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**Total**
Wandering	0.0%	0.1%	0.3%	3.6%	1.5%	3.0%	0.4%	8.8%
Verbally Abusive	0.4%	0.8%	0.5%	3.6%	0.9%	1.5%	0.4%	8.1%
Physically Abusive	0.1%	0.1%	0.1%	1.8%	0.8%	1.8%	0.6%	**5.3%**
Inappropriate/ Disruptive	0.3%	0.9%	0.6%	4.5%	1.6%	2.7%	1.6%	12.3%
Resists Care	0.8%	1.5%	0.8%	6.0%	2.0%	3.6%	2.0%	16.7%
Total Unduplicated	1.2%	2.5%	1.6%	**11.2%**	3.7%	6.2%	3.1%	**29.5%**

Source: Indiana Office of Medicaid Policy and Planning based on 2001 MDS data

The most common CPS score for each type of behavior symptom, including physically abusive behavior, is 3 = Moderate Impairment. Overall 11.2% of nursing home residents with one or more behavioral symptoms have a CPS score of 3.

OMPP and Myers and Stauffer suggest aggregating CPS scores of 4-6 (moderate to very severe impairment) to reflect residents who are cognitively impaired. The following table provides a breakdown of nursing home residents who exhibit behavioral symptoms and are cognitively impaired with scores of 0-3 and 4-6.

MDS 2001 Mood & Behavioral Pattern	Of residents with behavior, # with CPS Score of 0-3	Of residents with behavior, # with CPS Score of 4-6	Of residents with behavior, % with CPS Score of 0-3	Of residents with behavior, % with CPS Score of 4-6
Wandering	1601	1931	45%	55%
Verbally Abusive	2107	1143	65%	35%
Physically Abusive	853	1281	40%	60%
Inappropriate/ Disruptive	2540	2380	52%	48%
Resists Care	3665	3051	55%	45%
Total Unduplicated	6628	5183	56%	**44%**

Source: Indiana Office of Medicaid Policy and Planning

This table shows that overall 44% (less than half) of residents with one or more of the behavioral symptoms have cognitive impairment scores of 4-6. Sixty percent of residents with physically abusive behavior have CPS scores of 4-6. When a larger pool of cognitively impaired residents -- with scores of 3-6 -- are considered, MDS data shows that overall 82% of residents with one or more behavioral symptom have some degree of cognitive impairment and 94% of residents with physically abusive behavior have some degree of cognitive impairment. Depending upon the CPS scores included, somewhere between 60%-94% of residents with physically abusive behavior are cognitively impaired, while 6%-40% are not.

MDS 2001 Mood & Behavioral Pattern	Of residents with behavior, # with CPS Score of 3-6	Of residents with behavior, % with CPS Score of 3-6
Wandering	3370	95%
Verbally Abusive	2581	79%
Physically Abusive	2002	94%
Inappropriate/Disruptive	4204	85%
Resists Care	5476	82%
Total Unduplicated	9690	82%

Source: Indiana Office of Medicaid Policy and Planning

Further MDS data on Mood and Behavior Patterns and Cognitive Impairment within Indiana nursing facilities can be found in the OMPP publication **"Indiana Nursing Facility Resident Profile – Data for Years 1999, 2000, and 2001".**

Data from Indiana State Department of Health

To further define the scope of aggressive behavior among nursing home residents, the Working Group reviewed data provided by **the Indiana State Department of Health (ISDH),** which reported to the group on May 20, 2002. The presentation and handouts included the following information.

ISDH monitors compliance with federal and state regulations for over 600 nursing homes in Indiana (n=608), with 2,477 Medicare certified beds, 18,899 Medicaid certified beds, 31,864 Medicaid/Medicare certified beds, 11,635 non certified residential beds, and 2,460 non comprehensive care beds (NCC) (private pay) beds. About 40,000 residents occupy these facilities at a time (i.e. average daily census) and 75,000 over the course of a year (i.e. with turnover).

ISDH conducts surveys for each facility annually and investigates complaints from the public.

- *During the most recent six-month period (12-1-01 to 5-16-02) ISDH received **11 complaints from the public of resident-to-resident abuse**; if annualized this would equal about **22 complaints of resident-to-resident abuse per year**.*
- *During the same six-month period **long term care facilities reported to ISDH 571 incidents of resident-to-resident abuse** (of about 5,000 incidents reported by long term care facilities); if annualized this would equal about **1,142 incidents (of about 10,000 incidents reported by facilities per year).***

Additional ISDH data from survey reports is summarized in **Appendix 4**.

When surveying long term care facilities, ISDH collects data required by the U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services (CMS, formerly HCFA), including **CMS Form 672 Resident Census and Condition of Residents**. This form is completed by the facility to describe resident conditions **in Medicaid and Medicare certified beds** on the day of the survey. ISDH records based on this data show:

- A total of 18,105 nursing home residents had some form of dementia including Alzheimer's disease.
- Counties with the greatest number of dementia residents are Lake (Gary, Hammond, East Chicago), St. Joseph (South Bend), Allen (Fort Wayne), Marion (Indianapolis), Vanderburg (Evansville), and Clark (Louisville).
- Details from the census of residents in Indiana facilities follows:

CMS Form 672 Resident Census	**Number**

Total Residents	41,541
C. Mental Status	
F108 Mild retardation	1,840
F109 Depression	16,287
F110 Psychiatric diagnosis (excluding depression and dementia)	6,838
F111 Dementia including Alzheimer's	18,105
F112 Behavioral symptoms (wandering, verbally abusive, physically abusive, socially inappropriate/disruptive, resistive to care)	12,751
F113 Of F112, number and % receiving behavior management program	7,986 (63%)
F. Medications	
F133 Receiving any psychoactive medications	10,336
F134 Anti-psychotic medications	7171
F 135 Anti-anxiety medications	17092
F136 Antidepressant medications	2343

Like the OMPP MDS data, the ISDH data provides some insight into the extent of aggressive and abusive behavior among nursing home residents.

Data Limitations

Notwithstanding these efforts to provide usable data, the Working Group wishes to convey its concern regarding data limitations. The Group found it difficult to document the scope of this problem because much potentially valuable data is either not collected, not reported, or is self reported, resulting in inconsistencies from staff-to-staff and facility-to-facility. *Some researchers believe that even when behavioral incidents are reported, they are substantially underreported, for various reasons including time constraints, inadequate recognition of the importance of documenting behaviors, fear of liability, and fear of citation by surveyors.* For example, in her paper for an Institute of Medicine report on elder abuse, Catherine Hawes of Texas A&M University reported widespread underreporting of elder abuse by health care professionals and by resident and family members; one study she cited (Pettee, 1997) found that in Indiana 73% of nurses had observed abuse but only 36% reported it.

In 2001 a National Academy of Science Institute of Medicine panel was convened to Review Risk and Prevalence of Elder Abuse and Neglect. It was charged by the National Institute on Aging to assess the state of knowledge in this field and to make recommendations for future research. On June 17, 2002, its report entitled **"Elder**

Mistreatment: Abuse, Neglect and Exploitation in an Aging America" was released with the following major points:

- Very little is known about the nature and magnitude of elder abuse and neglect
- Prevalence data are urgently needed
- Though unquantified, the problem is serious and likely to grow
- Research is needed to respond effectively to the problem
- We need to build an infrastructure for research

Within the broader context of elder abuse, the June 2002 Institute of Medicine (IOM) report provides information on resident-to-resident aggression and recommends a research agenda for this and other dimensions of elder abuse. Indiana may wish to participate in more detailed studies if they are undertaken and funded by the federal government or private sources.

Studies already completed throughout the U.S. partially document the extent and nature of aggressive behavior. One such study that reflects the larger body of research and augments findings of the Indiana study -- a **study of Oregon nursing facility residents** -- is summarized in **Appendix 5.** Among its findings were these:

- 5.56% of Oregon nursing facility residents exhibited physically aggressive behavior according to the MDS but only 77% of these were documented in clinical records as having caused harm to others, for an adjusted physically abusive rate of 4.28%. *(Similarly, Indiana's MDS data revealed 5% with physically abusive behavior.)*
- 22% of the Oregon study group displayed aggressive behavior that resulted in actual harm to others.
- Extrapolating this to Oregon's whole nursing home population, from .6% to 1.08% of nursing facility residents engage in behavior that causes harm to others.
- Overall 80% of incidents of physically aggressive behavior were directed toward staff.
- Alzheimer's Disease emerged as a significant factor when harm groups were compared. Those residents who displayed the most serious and greatest variety of physically aggressive behavior all had dementia, while some of the residents who displayed milder forms of physically aggressive behavior did not. The severity of dementia, including Alzheimer's disease, or how well the symptoms of dementia are managed may be key factors that determine the severity of behavior.

2. Factors Contributing to the Problem in Indiana

SCR 18: Identify factors contributing to the above-identified problems.

Studies indicate that aggressive behavior is associated with a variety of factors, including but not limited to dementia.

Factors related to **residents include:**

- Previous history of violence/criminal record
- Untreated pain or other discomfort
- Medical conditions, such as urinary tract infections
- Depression, other mental illness, co-occurring disorders
- Males
- Mid to late stage Alzheimer's disease
- Other forms of dementia not related to Alzheimer's, such as head injury and alcoholism (younger and stronger residents with other dementias sometimes are placed in special care units for behavior management)
- Provocation by other residents and caregivers, often during assistance with Activities of Daily Living (ADLs)

Factors related to **facilities and the overall delivery system include:**

- Insufficient training on dementia and behavior management for professionals caring for the geriatric population (physicians, nurses, aides, etc.); insufficient use of behavior management techniques (environmental changes, acceptance)
- Inadequate use and training in proper use of medications
- Inadequate supply of caregivers specially trained in geriatrics, ranging from aides to nurses to social workers to physicians; not enough staff
- Beyond dementia, large numbers of nursing home residents with mental health needs contributing to aggressive behavior
- Insufficient early assessment and treatment of behavioral and mental health conditions, especially for residents excluded from pre admission screening & resident review (PASRR) due to the federal dementia exclusion
- Lack of awareness of reimbursement options available in Indiana for mental health services
- Shortage of geriatric mental health professionals in nursing homes, in private practice, and in community mental health centers
- Lack of highly specialized "Facilities of Last Resort" for treating behavioral disorders
- Limitations in reimbursement and regulation of dementia care in special care units
- Limitations in criminal justice and adult protective service systems

Factors related to residents: characteristics of dementia and aggression

On April 22, 2002, **Dr. Patrick Healey of St. Vincent Institute on Aging** addressed the Working Group. He summarized the literature and provided much of the following information on dementia related aggression in long-term care, behavior management, and treatment protocols including drug therapies. **Dr. Constantine Lyketsos** of Johns Hopkins School of Medicine, author of **Practical Dementia Care** and contributor to the **Institute of Medicine** report on elder abuse, provided additional information.

Dr. Healey pointed out that behavioral disorders in long-term care are not uncommon. They may be due to underlying psychiatric disorders, mental retardation, lifelong

personality disorders, degenerative dementia, agitated depression, and other factors. Dr. Lyketsos indicated (by interview) that key predictors of aggression are:

- Males with
- Depression
- Mid to late stage dementia
- History of violence

Of the 1.5 million nursing home residents in the U.S. about 60% have dementia; 60% of all dementia is Alzheimer's disease or Alzheimer's combined with vascular disease. Eighty percent of people with dementia experience some behavioral difficulties. The prevalence of Alzheimer's Disease is expected to grow, from 4 million people in 2000 to 8.7 million people in 2020 to 14.3 million by 2050.

Generally nursing home residents are older (average age of 85), have greater severity of dementia, more significant behavioral issues, more co morbid illness, and increasing frailty. Long-term care "has replaced psychiatric hospitals for care of elderly with neuropsychiatric disorders".

The diagnosis of dementia is based on having one or more of the following deficits:

- Aphasia – language disturbance, word finding problems
- Apraxia – inability to carry out motor activities
- Agnosia – failure to recognize or identify objects
- Disturbance in executive functioning – planning, organizing, sequencing, comprehending abstract concepts.

Cognitive problems must be sufficient to impair the person's ability to perform normally in social or occupational situations. The course is gradual and progressive, and no other illness or condition is responsible for the cognitive decline. The most common types of dementia are:

Type	**Percent**
Alzheimer's Disease	56%
Vascular causes or multi infarct dementia	14%
Multiple causes	12%
Parkinson's disease	8%
Brain injury	4%
Other*	6%
*Other includes Pick's disease, Diffuse Lewy Body Disease, Korsakoff's psychosis, HIV/AIDS, Jacob-Creutzfield, Neurosyphilis, B12 deficiency, Fronto-temporal dementia, and thyroid disease.	

Virtually any type of dementia can lead to virtually any behavioral problem. *The best predictor of violent behavior is a prior episode of violent behavior.* Alzheimer's Disease is progressive, with early, middle, and late/final stages. Behavioral problems begin in the middle stage. By the final stage patients are bedridden.

Aggression is estimated to occur in 60% of Alzheimer's patients' home settings. Estimates of aggression in long term care facilities range from 20%-81%. Estimates of psychosis in people with Alzheimer's Disease vary widely. The frequency of delusions reported in 21 studies range from 10% to 73% (median 33%). The frequency of hallucinations range from 21% to 49% (median 28%). Both are more likely to occur in mid to later stages.

Dr. Healey pointed out that aggression and agitation often are verbal rather than physical, often triggered during assistance with the activities of daily living (eating, bathing, dressing, toileting, ambulating, etc.) Many studies have shown that aggression is more often directed at caregivers/staff providing assistance, less commonly directed at other residents. Dr. Healey noted that changes – such as transfers/discharges across facilities -- are agitating and that aggression is exhibited in home and community based settings as well as nursing facilities.

When treating patients, Dr Healey and his counterparts seek to document underlying causes of agitation/aggression (defined by Cohen-Mansfield 1990). Precipitating factors may include neurodegeneration, cognitive dysfunction, previous experiences, current stressors, or prior psychopathology. Pain, physical discomfort, urinary tract infection, fecal impaction, recent trauma, and depression are common precipitating factors. Forty percent (40%) of people with Alzheimer's also have ongoing depression, a key issue discussed later. Sometimes behavior is the only form of communication residents have left. They cannot tell you what they want so they act out.

In a study of agitated behavior among residents of 53 Alzheimer's disease Special Care Units, Dr. Philip Sloane et al found that *"the proportion of residents exhibiting an agitated behavior varied from none in some units to 38% in one unit. Independent correlates of low unit agitation levels included favorable scores on measures of the physical environment and of staff treatment activities, low rates of physical restraint use, a high proportion of residents in bed during the day, small unit size, low levels of resident functional dependency, and fewer numbers of co-morbid conditions".*

Factors Related to Facilities/Delivery System:

Insufficient Use of Behavior Management Techniques and Insufficient Training on Dementia and Behavior Management for Professionals Caring for Geriatric Population

Dr. Healey noted that treatment should first include determination of whether a medical condition is responsible for the behavior. Surrounding physical stimuli should be minimized. Providers should determine whether behavior was spontaneous or provoked,

and whether behavior was related to care issues; often it is. Providers should identify triggers and attempt to remove them. Providers should consider whether non-drug treatments are available. *Physicians are dependent upon front line staff (aides and nurses) to identify conditions, record behaviors, and report them.*

Dr. Healey reported that behavioral therapy is considered the best method of treating agitated behavior. A combination of therapeutic modalities often is needed: medication, psychosocial services, environmental strategies, and caregiver education.

In his book **Practical Dementia Care** (pages 133-144) Dr. Lyketsos notes that dementia can be treated and managed by systematically addressing impairments. He recommends the 4D Approach:

- Define and describe the problem
    - Based on history, discussion with caregivers, physical exam, lab studies
    - When, where, how, with whom, and after what does the problem arise
- Decode the contributing causes
    - Cognitive disorder (aphasia, apraxia, agnosia, amnesia)
    - Psychiatric disorder or syndrome
    - Medical or neurologic illness or medication
    - Environment
    - Caregiver approach
- Devise a treatment plan
- Determine if treatment works

Dr. Lyketsos noted that it is exceptionally important for direct care staff to document time, place, and circumstances of aggressive behaviors in order to define the problem, decode the causes, devise a treatment plan, and determine if treatment works. He indicated that documentation is sometimes constrained by the facility's fear of citations by the state regulatory/survey process. *He was one of several experts/observers noting ironic examples of facilities with strong behavior management programs that documented behaviors in detail but were penalized by the survey process due to their detailed records of behavioral problems.*

The Working Group concluded that most aggressive behavior can be treated/minimized by facilities and their staff through expanded use of behavior management strategies. There is a wealth of training material and trainers available on ***dementia and progressive behavior management techniques****, however they are* ***not used consistently or often enough****. Training of staff on the front line of resident care (nurses, nurse practitioners, advanced practice nurses, nursing aides, etc.) is key because they are in the best positions to identify behavioral changes and respond. Training of attending physicians and family members also is needed.*

One behavior management "classic" is Lisa Gwyther's book on responding to challenging behaviors: **Caring for People with Dementia: A Manual for Facility Staff.**

Another training tool suggested by Indiana ombudsmen is **Choice and Challenge: Caring for Aggressive Older Adults Across Levels of Care**, A Training Video with Supportive Printed Material produced for the American Psychiatric Nurses Association in 1998. Choice and Challenge points out that aggression often *occurs during assistance with activities of daily living,* noting that aggressive behavior may be related to:

- Touch or invasion of personal space
- Frustration due to loss of ability
- Pain or fear of pain
- Loss of control or choice
- Inattention of personal needs or wishes
- Uncertainty, fear of the unknown

Choice and Challenge notes that staff who are well trained in behavior management, work regularly with, and have rapport with the residents are in a better position to minimize catastrophic reactions. Staff may minimize aggression by:

- Offering choices
- Respecting privacy needs
- Focusing on the person not the task
- Using calm personal gentle manner
- Taking time, not rushing
- Explaining what is being done
- Reducing noise, confusion, crowding, over stimulation, and competing demands for attention

Inadequate Use and Training in Proper Use of Medications

Dr. Lyketsos noted that medication should be considered: 1) when all other approaches have failed; 2) when the patient, caregiver or others are at risk of harm; or 3) when a specific psychiatric symptom or syndrome known to respond to medication is present. Even when medication is indicated, it is usually more effective to combine it with a behavioral-environmental approach. Antipsychotics, mood stabilizers, beta-blockers, and anti-depressants, alone or in combination with each other, have shown some efficacy in his experience.

Dr. Healey reported that if medications are indicated, physicians should follow proper protocols, starting with low dosages, such as ½ to ¼ of recommended adult starting doses. Side effects should be monitored. Medications for agitated and aggressive behaviors include:

- Neuroleptics are most effective but are controversial; due to side effects they are sometimes interpreted as chemical restraints.
- Benzodiazepines and sedatives should be avoided.
- Anticonvulsants are effective in diminishing impulsive behavior.

- Antidepressants should be used if there are any signs of depression (again, depression is key because 10% of AD patients have major depression and another 15-25% have significant depressive symptoms).
- Acetyl cholinesterase inhibitors may be helpful in postponing behavioral issues.

There are many pharmacologic options approved for specific uses, but there is no FDA approved treatment for aggressive behaviors and no one class of therapeutic agents can be used to treat all cases of agitation. Some are better for verbal aggression, others for stabilizing mood or reducing anxiety, and so on. Consequently, use of drug treatment requires specific training.

Dr. Healey noted that guidelines/sequences/protocols have been developed for treating dementia, mental health, and co-occurring disorders in the elderly with behavior management and drug therapies, but that some generalist physicians and medical directors of nursing homes are not aware of proper protocols. This can result in negative consequences for elderly patients. For example certain medications widely used to treat depression in the general population have side effects or are counterproductive for the elderly. Physicians sometimes hesitate to use medications, fearing OBRA citation for "pharmacologic restraints", even when they are needed and could be effective.

More physicians need training in proper treatment protocols, including drug treatment, for the elderly with behavior management problems. Professionals in health, mental health and long-term care settings need to be trained to use proper treatment protocols, including drug protocols.

State officials should strive to ensure that appropriate medications/protocols are included on the preferred drug list under development by the Drug Utilization Review Board of Medicaid.

Inadequate Supply of Caregivers Specially Trained in Geriatrics, Ranging from Aides to Nurses to Social Workers to Physicians; Staff Shortages

Numerous reports have documented the shortage of nurses and nursing aides in long term care. In her paper for the National Academy of Sciences IOM report on elder abuse, Catherine Hawes of Texas A&M University reported widespread agreement that **three factors** contribute to elder abuse in long term care facilities:

- Stressful working conditions particularly staffing shortages
- Staff burnout, often a product of staffing shortages and mandatory overtime
- A combination of resident aggression and poor staff training on how to handle such challenging behaviors

She cited a recent study by HCFA (2000), hearings before the U.S. Senate Special Committee on Aging (1998) and reports by GAO and OIG of the U.S. Department of Health and Human Services that identified staffing problems as major impediments to quality of care in nursing homes.

*There is a shortage of **geriatric trained health professionals** nationwide*, as reported by the Indianapolis STAR on May 6, 2002:

"Geriatricians are doctors with expertise in caring for older people. Most are trained in family practice or internal medicine but have completed one additional year of fellowship training in geriatrics and passed a certifying exam…Health officials are sounding the alarm… in a county where the number of elderly is on the rise, there are too few health providers knowledgeable about aging issues…The shortage of geriatric-trained health care professionals is reaching crisis levels…Fewer than 9,000 of the nations 650,000 licensed physicians have met the qualifying criteria in geriatrics and that number is expected to drop to 6,100 by 2004."

The Working Group concluded that in order to address demographic increases in the elderly and cognitively impaired population, more specially trained professionals are needed. More caregivers should be specially trained in geriatrics across a spectrum ranging from nurse aides (CNAs) to LPNs, RNs, nurse practitioners, advanced practice nurses, social workers, mental health practitioners, and physicians. Some Working Group members advocated more staff per patient.

Training of physicians is critical. Indiana could strive to increase the supply of geriatricians and geriatric psychiatrists in the same way that the state and IU School of Medicine promoted family practice medicine and increased the supply of family practice physicians. The School of Nursing could assist by producing more nurse practitioners and advanced practice nurses to help fill the void as well.

*Human resource needs could be referred to the **Governor's Commission on Caregivers for the Continuum,** a group already working on these issues, for further consideration.*

Beyond Dementia, Large Numbers of Nursing Home Residents Have Mental Health Needs Contributing to Aggressive Behavior

Various sources indicate that co-occurring dementia and mental illness contribute to aggressive behavior. For example, Dr. Healey and Dr. Lyketsos reported that as many as 40% of people with dementia have co occurring depression, often untreated.

Consequently Willard Mays, Assistant Deputy Director for Policy Development, Indiana Division of Mental Health and Addiction, was invited to address the Working Group on May 6, 2002. In addition to serving as a state official, Mr. Mays is a national expert on mental health and aging, and is past chair of the National Coalition on Mental Health and Aging, which includes over 50 federal agencies and national organizations. His general premise was that mental health needs of older adults are not being adequately addressed in or out of nursing homes. Mental health issues for elders were enumerated at the 1995 White House Mini conference of Mental Health and Aging and reasserted in 1999 at a major conference of the National Coalition on Mental Health and Aging. Further information is available from the American Psychological Association, Office on Aging

and the American Society on Aging's Mental Health and Aging Network. DMHA reported as follows:

- A significant number of Indiana nursing facility residents have a diagnosed mental disorder based on 2001 MDS data updated for this study by OMPP:

Disorder	**DMHA 1990s**	**OMPP MDS 2001**
Alzheimer's disease	13.7%	17.4%
Dementia other than Alzheimer's disease	31.6%	34.8%
Depression	26.7%	39.4%
Anxiety disorder	11.2%	14.6%
Schizophrenia	3.3%	3.6%
Manic depression (bipolar)	1.6%	2.1%

  Source: Indiana Division of Mental Health and Addiction; Indiana Office of Medicaid Policy and Planning based upon 2001 MDS data

- By far the most common treatment for mental illness in nursing facilities is medication (98%).

Treatment	**DMHA 1990s**	**OMPP MDS 2001**
Anti-psychotic medication	19.80%	26%
Anti-anxiety medication	17.50%	16%
Anti-depressant medication	29.30%	43%
Psychological therapy	1.12%	1.2%
Evaluation by licensed mental health specialist (last 90 days)	8.20%	14.9%

- Source: Indiana Division of Mental Health and Addiction; Indiana Office of Medicaid Policy and Planning based upon 2001 MDS data
- Mental health services for nursing facility residents are not typically provided by facility employees. They are provided by psychiatrists, clinical psychologists, and clinical social workers, which provide services on an outpatient basis and then bill the appropriate funding source. Clinical social workers are most frequently used due to their wider availability and lower costs.

- The typical nursing facility resident with a mental illness is evaluated by a mental health professional on the average of once every three years.

Insufficient Early Assessment and Treatment of Behavioral and Mental Health Conditions, Especially for Residents Excluded from Pre Admission Screening & Resident Review (PASRR) due to the Federal Dementia Exclusion

The combination of dementia and depression is fairly common and is associated with aggressive behavior among nursing facility residents, particularly when untreated. Data indicates that early assessment and treatment of behavioral, mental health and other needs is a key to preventing aggressive behavior. However, several sources indicated that the dementia exclusion in pre admission screening limits the extent to which dementia patients with co occurring mental illnesses are screened and treated. Therefore Rebecca Koors of FSSA was invited to describe Indiana's Pre Admission Screening and Resident Review process at the April 22nd meeting of the Working Group. She presented the following information.

Indiana instituted pre admission screening (IPAS) in April 1983, before the federal government did so. Screening is conducted to determine whether individuals meet minimum state standards for placement in a nursing home and to prevent inappropriate placement in nursing homes. Further, in order to qualify for Medicaid reimbursement, residents must meet financial and medical requirements, the latter determined through the pre admission screening process.

In 1987 the federal government began to require pre admission screening and resident review (PASRR) pursuant to the Omnibus Budget Reconciliation Act (OBRA) (nursing home reform law). The purpose is to assess medical *and psychiatric needs,* ensure that those needs are met, and prevent inappropriate placement of *seriously mentally ill* persons in nursing homes.

The Indiana pre admission screening and resident review process currently includes the following screening tools; **copies are provided in Appendix 6:**

- Long Term Care Application - completed by the family.
- Level I - completed by the doctor, nurse, hospital, nursing facility; the area agency on aging certifies the document indicating if a Level II is required.
- 450 B - completed by a medical professional/physician (identifies medical needs).
- Level II - completed by a community mental health center (CMHC) (identifies mental health needs).

In Indiana, doctors, nurses, hospitals, nursing facilities and area agencies on aging complete Level I screening; they identify medical needs including dementia and Alzheimer's disease, senility, and mental illness. Screening is used to determine whether nursing home placement is appropriate. Indications of mental illness trigger a more rigorous Level II screen by a community mental health center or hospital (except in cases of **the "dementia exclusion"** discussed below). For a Level II screen, the CMHC does a

comprehensive assessment including recommended treatment, medication monitoring, care plan, and determination of nursing home placement.

In 1987 the Alzheimer's Association lobbied successfully to exclude people with a primary diagnosis of dementia from PASRR mental health screening requirements because it believed that people with dementia had different issues and that they were already protected by other OBRA requirements. According to federal policy, the PASRR Level II (mental health) assessment therefore has a "dementia exclusion" which waives the Level II assessment for people with a primary diagnosis of dementia, regardless of co-occurring mental illness such as depression. (The dementia exclusion applies only to mental illness, not to developmental disabilities; the federal government requires a Level II screen for people with co occurring dementia and developmental disabilities.)

While the dementia exclusion was sought by consumer advocates to ensure access to nursing homes for people with dementia, it may have resulted in unintended negative consequences. As documented later, if their needs are not assessed, some nursing home residents with co occurring dementia and mental illness may not always get needed mental health treatment.

The Indiana State Department of Health (ISDH) relies in part on PASRR screening tools when conducting surveys. ISDH monitors facilities' compliance with care plans to ensure that residents are getting the recommended treatment. If no Level II or other mental health assessment is done, ISDH lacks an objective basis for determining that treatment is needed and for monitoring/enforcing the provision of treatment. People with dementia thus may not benefit fully from the consumer protection theoretically afforded by ISDH inspections.

Technically, regardless whether a Level II assessment is conducted prior to admission, the nursing facility can request an assessment at any time (e.g. for change of mental health condition) and is responsible under OBRA for assessing needs, developing a care plan, and treating the needs identified at entry and upon a change of condition.

However, as discussed in the section on mental health and geri-psychiatric services, nursing facilities report that they often lack in-house expertise for assessing and treating mental health needs and they have difficulty getting mental health professionals, including community mental health centers, to treat their residents. Working Group members, including long term care providers, concur that pre admission Level II assessments by CMHCs help facilities develop proper care plans.

Opinion is mixed regarding the overall effectiveness of pre admission screening, but the Indiana PASRR program appears to be successful in getting nursing facility residents plugged into appropriate services for *serious mental illness* when services are recommended by PASRR. DMHA reported that *87% of residents determined by PASRR to need mental health services are receiving some or all of the recommended services. DMHA concluded that in Indiana people who received a PASRR assessment fare better in receiving appropriate services than those who do not.* Indeed, a description of the

Indiana PASRR program is featured in the DHHS publication **Promoting Older Adult Health: Aging Network Partnerships to Address Medication, Alcohol and Mental Health Problems**; the follow up process used to assure that identified mental health services are actually provided to nursing home residents appears to be unique in the county.

The Working Group concluded that early assessment and treatment of mental health needs, notably depression, is a key to preventing aggressive behavior. For those residents exempt from PASRR Level II, other methods should be used to assess mental illness. A range of possibilities exists, short of seeking a federal waiver of the PASRR Level II "dementia exclusion". Other than requiring the full Level II process, the state could encourage facilities, physicians, and families to refer clients for mental health needs assessments and psychiatric evaluations. Facilities should train staff to identify possible mental illness; they should be encouraged to assess, develop care plans, treat, and monitor mental health needs as required by OBRA and to contact DMHA for assistance when they cannot locate mental health providers. The Indiana Department of Mental Health could provide incentives and otherwise encourage mental health providers including CMHCs to offer comprehensive mental health screening/assessment services to nursing facilities. PASRR Level II screening is reimbursed at up to $360 per person and DMHA reports that Medicaid, Medicare, private insurance and other funding sources are usually available for non-PASRR mental health assessments when requested by the resident, facility, or the attending physician.

DMHA reports that Medicaid/Medicare reimbursement is available for non-PASRR mental health assessments when requested by the facility/attending physician.

Lack of Awareness of Reimbursement Options Available in Indiana for Mental Health Services

While lack of reimbursement options is sometimes a barrier to providing services, many reimbursement sources are available in Indiana for mental health services: private pay (community mental health centers use sliding scales), insurance, Medicare, the Hoosier Assurance Plan (HAP), regular Medicaid, and the Medicaid Rehab Option (MRO). *Both Medicare and Medicaid fund mental health services for the elderly.*

In 1999, Medicare expanded coverage to include a larger pool of mental health professionals -- clinical social workers -- furnishing services to inpatients of nursing homes. In September 2001 the Centers for Medicare and Medicaid Services (CMS) issued a program memorandum about Medicare reimbursement of people with dementia. Among other things it indicated that:

- Medicare cannot refuse to pay for some medical services for beneficiaries with Alzheimer’s disease solely because of their diagnosis. In some regions of the country Medicare was denying needed medical care because of the incorrect belief that an individual with Alzheimer’s disease cannot benefit from various interventions.

- Medicare will cover psychotherapy or other behavior management therapy provided by a mental heath provider for an Alzheimer's beneficiary if the therapy is reasonably and necessary.

The Indiana Division of Mental Health and Addiction confirmed that Medicaid reimbursement is available for mental health services in Indiana nursing homes, over and above the regular nursing home per diem rate. DMHA provided a March 15, 1991 memo on Medicaid policy stating:

Community mental health centers may provide outpatient mental health services off site, such as in a nursing facility, as long as the requirements of 470 IAC 5-8-13 and 470 IAC 5-9-22 are met. Medicaid Prior Authorization will accept either a PASRR/MI Level II assessment or a mental health assessment that shows the need for mental health services. Prior authorization is required for outpatient mental health services that exceed 20 units per year, per recipient, per provider. Prior authorization must be requested by a physician (MD or DO) or health service provider in psychology (HSPP). The PASRR/MI Level II assessments are exempt from the prior authorization process.

DMHA thus indicated that based on a physician's order, an initial assessment, and up to 20 units of mental health services may be provided annually to Medicaid eligible residents without prior authorization. If the need exceeds 20 units of service annually, the PASRR Level II assessment or another mental health assessment may be used as documentation to request additional service through the prior authorization process.

The Medicaid Rehab Option adds more flexible services -- such as case management and transportation -- provided by a broader pool of professionals – such social workers. Only community mental health centers can access the MRO. CMHCs provide the state match needed to draw down federal reimbursement.

DMHA reported that nursing homes and their trade associations are not fully aware of these Medicaid and Medicare mental health reimbursement alternatives. Facility representatives on the Working Group confirmed this. Consequently, the Working Group recommends that Medicare and Medicaid reimbursement options for mental health services be publicized and marketed so that more families and facilities will take the initiative to access needed services. Consumer groups and trade associations could invite OMPP, DMHA, ISDH, and Bureau of Aging and In Home Services to provide pertinent information on this topic during periodic meetings of their members.

Shortage of geriatric mental health professionals in nursing homes, in private practice, and in Community Mental Health Centers (CMHCs)

Even with early identification of mental health needs and Medicare/Medicaid reimbursement available for treatment, there remains a critical issue with the current and projected shortage of qualified mental health professionals, especially in rural areas.

Facilities indicate that a general shortage of mental health professionals is the underlying problem. They report that there are not enough qualified people to ensure adequate treatment and that attending physicians – often generalists in family practice and internal medicine -- may inadvertently order the wrong medications/treatment. As indicted earlier, nursing homes generally do not offer mental health services in-house. Family members and nursing facilities must locate treatment providers on their own.

In Indiana all 92 counties (100%) have at least one nursing facility, yet many do not have access to qualified mental health professionals. Data collected by DMHA in 1999 from the Indiana Health Professions Bureau and Indiana Psychiatric Society show that:

- 64 counties (70%) did not have a psychiatrist
- 23 counties (25%) did not have a clinical psychologist
- 4 counties (4%) did not have a clinical social worker
- 3 counties had none of these three types of mental health professional
- Licensed mental health professionals are not equitably distributed throughout the state. They are concentrated in urban areas; 38% of mental health professionals work in the Indianapolis metropolitan area. Details follow:

Distribution of Indiana Mental Health Professionals	**Number/%**
Psychiatrists (statewide)	336
Counties with no psychiatrist	64
Percent of total in Indianapolis metropolitan area	54%
Clinical Psychologists (CP) (statewide)	1030
Counties with no clinical psychologist	23
Counties with 1 clinical psychologist	21
Percent of total in Indianapolis metropolitan area	30%
Clinical Social Workers (CCSW) (statewide)	3029
Counties with no CCSW	4
Counties with 1 CCSW	5
Percent in Indianapolis metropolitan area	39%
Counties with no psychiatrist or clinical psychologist	23
Counties with no psychiatrist, CP or CCSW	3

Source: Collected in 1999 by Indiana Division of Mental Health and Addiction from Indiana Health Professions Licensing Bureau and Indiana Psychiatric Society

Moreover, there is a reported a lack of mental health professionals specialized in geriatric training in mental health centers and in private practice. In its recent

publication, **Promoting Older Adult Health – Aging Network Partnerships to Address Medication, Alcohol, and Mental Health Problems**, the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Administration, described a model program for cross training in aging, mental health, and substance abuse (pages 88-91). The program, ElderReach, is sponsored by the Mental Health Coalition of Indiana Kentucky and Ohio.

Compounding the shortage of mental health services, the Indiana Division of Mental Health and Addiction confirmed that CMHCs are not mandated to provide services to the elderly or to nursing home residents (although they are required to provide crisis services to anyone needing such services and are required by state contracts to perform PASRR assessments). Consumers and their advocates throughout the state report that, with the exception of PASRR, some CMHCs will not assess or treat nursing home residents. For example, one facility with a 150-bed special care unit reported that during the past ten years the local community mental health center agreed to provide outpatient treatment for only one (1) resident. Southlake Mental Health Center reported that it currently has 7 psychiatrists on its staff but only one (1) is willing and specifically qualified to treat older adults. The CMHC is accredited by JCAHO, and must prove staff competence to treat patients *by type of diagnosis and by age of patient* in order to maintain accreditation and minimize liability issues. Although some CMHCs do have special skill in aging and geri-psychiatric services, others have determined that they lack capacity to serve the elderly.

The Working Group supports efforts to increase the supply of mental health professionals generally and of professionals with geriatric training/cross-training specifically.

Given that Community Mental Health Centers are no longer limited to delivering services within geographic catchment areas and that some but not all have special skill in aging and geri-psychiatric services, the Working Group recommends that CMHCs interested and able to deliver specialized aging services be identified and marketed throughout the state. Further efforts and incentives may be required to encourage CMHCs to deliver services to the elderly nursing home population.

One of the keys is to bring mental health and psychiatric care on site, into long term care settings, rather than to move or transfer patients. Numerous sources indicate that movement/transfer of patients can increase agitation/aggression.

Impact of Regulatory Processes; Involve Regulators

Many of the foregoing issues and solutions require the support of regulators. For example, national and local experts concur that direct care staff must carefully document behaviors in order to develop appropriate treatment plans; yet they report that actual citations and fear of citations through the survey process inhibit facility staff from aggressively documenting incidents and behaviors that could be useful in optimizing treatment.

To minimize barriers that could inhibit use of behavior management, ISDH, consumer groups, and providers should work together to provide incentives for documentation and behavior management. ISDH surveyors should receive ongoing training regarding behavior management strategies, appropriate medications/protocols for residents with aggressive/behavioral issues, mental health needs, and the importance of using Level I screens and MDS data to hold facilities accountable for meeting mental health needs.

Lack of Highly Specialized "Facilities of Last Resort" for Treating Behavioral Disorders

Absent in-house expertise, nursing facilities periodically transfer residents with behavioral problems to psychiatric units in hospitals for stabilization and medication management, then readmit them, usually within 30 days due to reimbursement limitations. However, ombudsmen and advocates report that facilities sometimes refuse to *readmit* the most difficult residents. The most difficult residents may be moved from facility to facility, ultimately "dumped" into facilities with high vacancy rates, the ones least qualified to treat patients.

The Working Group attempted to document the extend to which this occurs by reviewing ISDH records, but data was not available in part because transfers sometimes are handled informally and in part because data is not reported to or aggregated by the state. Newspaper articles periodically document examples around Indiana and numerous examples were presented anecdotally to the Working Group.

Experts and Working Group members concur that the first and best treatment is behavior management by properly trained staff within the nursing facility. However, for a small subset of the total nursing home population with behavioral symptoms, something more may be needed. Indiana MDS data shows that at a point in time only 2,134 (5%) nursing home residents are physically abusive and 1,276 (3%) have behavior that is hard to change. Some of these might benefit from highly specialized care, potentially beyond the services available in a regular nursing home or special care unit.

There are a few examples of nursing homes specialized in behavior management in the United States – in New Jersey and Minnesota for example – and a similar model is currently under development in Northwest Indiana. The Northwest Indiana model is described below and other state models area described later in the Section on Alternative Care in Other Communities/States.

Northwest Indiana Model

Lee Strawhun, CEO of the Southlake Community Mental Health Center, presented an innovative model to the Working Group at its May 20, 2002 meeting. The model began in an effort to address co occurring mental and physical disorders. It entails collaboration among nursing facilities, the community mental health center, and hospitals in the northwest Indiana region. All of these facilities had experienced difficulty in addressing extreme behavioral needs. People from nursing homes were being admitted to hospital

psych units then nursing homes were refusing to readmit the patients. Hospital discharge planners lacked placement options with follow along services for their clients. They wanted mental health centers to accept these clients, but centers did not have qualified staff. Mental health centers had psych patients who were aging, but nursing homes would not accept them. For example 28 nursing homes were contacted for one patient, but none would accept the patient. Fortunately for residents of Northwest Indiana, there are two nursing homes with special care units **for behavior management** in Illinois, but a solution was needed closer to home, in Indiana.

Collaborators decided to attempt creation of a **regional hub,** a unit with highly specialized mental health and aging services combined. One nursing home chain has agreed to dedicate a **15-17 bed unit** with its own entrance and segregated space as a behavioral unit. Local planners have established stringent admission criteria, focusing on:

1. people leaving hospitals, meeting PASRR screening for nursing homes, with a psychiatric diagnoses per Level II screening, and whose needs cannot be met in regular nursing home settings;
2. people already in nursing homes but whose psychiatric condition declines/decompensates; and
3. people discharged by community mental health center inpatient units.

The key to the facility is its staffing plan. Collaborators are being exceptionally careful to recruit and hire a director with experience in both mental health and aging. The facility will blend staffing from the CMHC with regular nursing facility staff. CMHC mental health staff will be assigned to work on site at the facility six days a week during the day. Nursing staff levels will be maintained but will be shifted to the evening, resulting overall in more staff per patient. The CMHC will provide 3.6 FTE licensed mental health professionals (1.6 FTE masters level and 2.0 FTE bachelors level) and a geriatric psychiatrist four (4) hours per week. The cost of these mental health services should total about $130,000 per year for mental health service to 15 patients (90% occupancy).

Reimbursement will be structured within the current system with current rates not requiring rule changes. The nursing home will charge its normal per diem and the mental health center will bill Medicare and the Medicaid Rehab Option as usual. The CMHC will provide the state/local match for the Medicaid Rehab Option, while drawing down federal funds to pay for 60% of the cost of services. The CMHC estimates that the space and staffing provided by the nursing home will result in sufficient savings to compensate the CMHC for its 40% contribution/match.

Partners do not anticipate indefinite lengths of stay for residents of the unit. They estimate the average length of stay will be 75 to 120 days (well over the 30 days currently offered but less than the Working Group goal of unlimited stays if needed by some residents). Currently, to meet medical necessity requirements for reimbursement of CMHC intensive services, patients' probable presenting condition must improve or service cannot continue.

Partners anticipate stabilizing residents then returning them to host nursing homes. The CMHC plans to provide follow along services once residents are discharged to host nursing homes. It will provide ongoing staff training for the model nursing home unit. *It may also provide technical assistance to facilities throughout the region.*

Partners will be ready to open within 90 days of finding a qualified director through the recruitment process underway.

The CMHC views the project as a possible segue into broader provision of older adult services, not just in institutional settings. It acknowledges that its "penetration rate" for older adult services is low, that older adults may have had mis-medication due to lack of expertise, and that clients' conditions may well improve as a results of its services.

Based on this and similar models, to address the very small number of residents (less than 1,000) whose behavioral symptoms are exceptionally difficult to treat in regular long term care facilities, the Working Group recommends the establishment of a few long term care facilities specialized in behavior management. Facilities should be small and have very stringent admission criteria to prevent "dumping". Facilities should be regional (for example 1 north, 1 central, 1 south) or in major population centers to ensure access for family members. Facilities should retain adequate numbers of highly specialized staff. They should also provide outreach, technical assistance and training on behavior management and medication to other facilities within their region. They should be reimbursed at a special rate if necessary to reflect their highly specialized services and potentially higher levels of care.

Further planning is needed to address the regulatory framework for this model, eligibility requirements, and reimbursement policies. Planning should include representatives of consumers, the health care profession, and the state (Division of Mental Health and Addiction, Department of Corrections, Division of Aging and Rehabilitative Services, Office of Medicaid Policy and Planning, Department of Health).

Limitations in Reimbursement and Regulation of Dementia Care in Special Care Units

The FSSA Office of Medicaid Policy and Planning reported on a detailed time study conducted in Indiana to assess the adequacy of Medicaid reimbursement for nursing home residents with Alzheimer's and related dementias, in both regular and special care units. The results of the study were published in **Cognitive Disorders and Resource Use Among Nursing Home Residents in Indiana**, March 31 2000, with further analysis published June 23, 2000.

Since October 1, 1998, Indiana has used case mix reimbursement for Medicaid, adapted from the resource utilization groups (RUGS) used by Medicare. The case mix system uses four components (direct care, indirect care, administration, and capital); only the direct care component is adjustable. Adjustments are made quarterly based on each facility's resident acuity level. A case mix factor is applied to each resident ranging from

0.5 minimum to 5.0 maximum. The overall average acuity level is .91-.92. Residents in the behavioral subgroup average only .6-.8, however residents with dementia often are grouped at a higher level due to their medical needs, which exceed and are reimbursed at a higher rate than their behavioral needs alone would indicate.

At the risk of oversimplifying a very complex study, researchers found that:

After analyzing resource use with the context of the RUG system…the RUG classification system adequately represents current resource use patterns for many cognitively impaired residents ***on regular nursing units****…on the other hand, RUG does not seem to fully reflect resource use* ***on Alzheimer's unit residents****. Even after taking ADL differences into account, many Alzheimer's unit residents received more direct care (****particularly unlicensed staff time****) than either cognitively impaired or non-cognitively impaired residents on regular units.*

To date, findings from this study have been tabled for reasons including: 1) state budget constraints, 2) the need to document whether the additional services in special care units result in positive outcomes for residents compared to general units, and 3) the need to define/set standards/develop regulations for special care units prior to reimbursing them at a higher level.

The Working Group recommends that findings from the FSSA Office of Medicaid Policy and Planning ***time study on reimbursement of dementia care in Indiana's special care units*** *be addressed once budget and further information needs are met. The group concurs that it will be necessary to define/regulate what makes special care units special prior to reimbursing them at a higher level.*

In addition, the Working Group recommends that FSSA OMPP consider a similar study for residents with behavior symptoms, with and without cognitive impairments. Other studies imply that dealing with difficult behaviors may require additional staff time regardless whether residents are cognitively impaired.

Limitations in Criminal Justice and Adult Protective Service Systems

Finally, the Working Group recommends further ***study of legal/justice system issues*** *surrounding elder abuse and the aging of people with violent and/or criminal histories. Adult Protective Services agents had a 150% increase in reported cases of elder abuse nationwide from 1986 to 1996. Moreover while the Working Group focused on aggressive behavior among nursing home residents with dementia, comparable attention could be placed on residents with violent/criminal histories. While justice system issues and solutions were beyond the scope of this study, it became apparent that dementia/cognitive impairment does not fully explain behavioral issues in nursing homes. Cases, such as the one in Evansville, can be traced to people with histories of violence as well as cognitive impairment.*

The correctional system must address the aging in place of convicted offenders, as **underway at the New Castle facility**. One behavior management facility in Minnesota accepts referrals from nursing homes and from correctional facilities. Different solutions will be needed for offenders under court supervision and for ex offenders or people with violent histories not under court supervision. Requirements for reporting abuse and criminal activity must be reviewed for applicability to this population. Cognitively impaired people technically may commit crimes yet they don't fit conveniently into the correctional, mental health, or long term care systems.

Some resident aggression issues fall within the broader subjects of elder abuse and "elder justice" under consideration by the U.S. Senate Finance Committee and Senate Special Committee on Aging. In a June 18, 2002, presentation to the Senate, the National Committee for the Prevention of Elder Abuse recommended that "elder abuse and neglect must become a priority crime control issue; the justice system including law enforcement, prosecution, corrections, judiciary, medial examiners, coroners, public safety officers, victims advocates, adult protective service workers, and ombudsmen must work as a coordinated system to protect victims, hold offenders accountable, and prevent future offenses."

3. Alternative Care in other Communities/States

SCR 18: Identify alternative types of care being utilized in other communities to address the above identified problems.

The National Public Policy Division of the Alzheimer's Association conducted an extensive search of other communities/states for alternative care models but reported that little has been done in the United States to address problems with aggressive behavior. Although the Working Group had planned to devote one meeting to reviewing models from other communities/states, insufficient information was available to justify such a meeting. This section summarizes the information that was collected by the Alzheimer's Association, Indiana Association of Homes and Services for the Aging, and Indiana Ombudsmen.

One model of particular interest to the working group is under development in **Northern Indiana**. The model entails a new level of collaboration among nursing homes, the community mental health center, and hospitals in the region. Lee Strawhun of Southlake Community Mental Health Center presented this model to the working group on May 20, 2002. It was summarized earlier in the section on highly specialized "facilities of last resort" for addressing behavioral symptoms. Another model of interest – specialized facilities in **New Jersey --** is discussed at the end of this section.

The **Indiana Association of Homes and Services for the Aging** provided the following information on solutions in other states, but most respondents/members merely confirmed the problem, not the solution(s):

- **Minnesota** has a state-operated, Medicaid certified nursing home that specializes in residents with severe behavior problems. All residents of this facility have been transferred from another nursing home or have been transferred from the Department of Corrections (DOC). DOC is becoming a more important source of residents because of the aging in place of criminals who develop health needs along with their behavior problems. The facility is expensive – and it scores at the 100th percentile for antipsychotic medications – but Medicaid provides a substantial amount of federal funding. The facility is popular with other facilities because it takes residents with the most difficult behaviors and because it has a strong outreach, training and consultation program that helps other facilities deal with behavior problems.
- **New York** reported that behavioral issues are a big problem. Six years ago, New York added regulations to provide for violent individuals. The regulations (Section 415.39 "Specialized Programs for Residents Requiring Behavioral Interventions") address special care units and are on the state health department's web site. Reportedly few facilities have opted for this alternative primarily due to physical plant requirements (difficult for existing facilities to retrofit) and insufficient reimbursement.
- **Florida** reports that aggressive behavior is a serious problem. The Florida nursing home profession has asked the regulatory agency to work with providers on best practice guidelines so that providers know what to do to avoid problems. Florida does not have any long term care facilities that can accept residents that need long term psychiatric care and nursing home care -- except at one or two state institutions which have very restricted entry.
- **Connecticut** reports hearing about similar problems frequently. It has one specialized geri-psych inpatient unit but stays there are generally short, for evaluation and medication tune-ups. Some staff training has been done on a limited basis.
- **Texas** reports the same problems, where violent residents go to a psych unit and are put on medications until stabilized, but then return to the nursing home. Its state agency for mental health and mental retardation and local advocate groups are working to improve the current law.

The Alzheimer's Association Public Policy Division collected articles on the subject through its library, research services, and network of contacts. It sought information about other states from sources including the National Association of State LTC Ombudsman Programs (NASOP), National Ombudsman Reporting System (NORS), Elder Abuse ListServ, University of Iowa, American Bar Association Commission on Legal Problems of the Elderly, and Administration on Aging. It concluded "*There is an apparent lack of national data on the scope of the problem and on statutes and regulations involving appropriate care for nursing home residents with dementia who cause harm to other residents and staff…the state of Indiana through the interim study committee is at the cutting edge of policy and recommendations on the issue of challenging behavior."* (See April 15, 2002 memo). Although it found little useable data on a national level, the Association provided the following information from other states:

- **Michigan** uses a definition of serious mental illness that includes co-occurring dementia (Michigan Statutes Annotated MSA 14.800): *"Serious mental illness…includes dementia with delusions, dementia with depressed mood, and dementia with behavioral disturbance but does not include any other dementia unless the dementia occurs in conjunction with another diagnosable serious mental illness…"*
- **Minnesota** has at least two facilities that specialize in challenging behaviors. One is the University Good Samaritan home in Minneapolis and another is Ah-Gwah-Ching, a state operated nursing home.
- Since 1993 **Alabama** has provided a separate line item appropriation for dementia training ($400,000 in FY 2000) pursuant to the 1993 Dementia Education and Training Act.
- There are **three behavioral management units in New Jersey** nursing homes. The units receive additional reimbursement under LTC regulations as special care units. The rates vary by facility and involve a complex formula. The added amount is usually substantially more than the nursing facility rate – it is usually the difference between the per diem SCU rate and the NF rate. The units are required to have special protocols and usually involve a more intensive approach to care. They are not restricted to individuals with dementia, but do include a variety of individuals with severe behavioral problems, some of whom may have dementia, who cannot be mainstreamed into the traditional nursing home setting and who can benefit from a stable environment, special interventions, and more intensive staff coverage and involvement. The three facilities are Christian Health Care (40 beds) in Wyckoff, Silver Care (40 beds) in Cherry Hill and Absecon Manor (32 beds) in Atlantic County.

  See Appendix 7 for a copy of the New Jersey regulations governing these special care units. The regulations contain provisions very similar to the model envisioned by the working group. They allow up to one 32-bed unit in each region of the state with specialized long-term care for "patients with severe behavior management problems such as aggressive and disruptive behavior". Facilities are required to have an affiliation with a nursing school, social work school and medical school to provide ongoing clinical training and research. Facilities also must have admission/discharge policies with priority for patients difficult to manage. They must have a medial director with experience in behavior management. They must maintain an ongoing program whereby staff members are available to offer other area health facilities in the region training, educational seminars, and technical assistance in caring for residents with behavior management problems. Further info is available from the New Jersey Dept of Health and Senior Services.

4. Recommended Action

SCR 18: Recommend action to ameliorate the above-identified problems and provide for the improved health and safety of individuals suffering from the effects of dementia or

related diseases, for other residents with whom they live, and for the staff charged with caring for such individuals.

While originally emphasizing aggressive behavior among nursing home residents with dementia, the Working Group developed a set of findings and recommendations that may be applied to aggressive behavior potentially harmful to a variety of people in a variety of settings. This section summarizes the recommendations discussed throughout this report.

The data currently available indicates that the portion of nursing facility residents who are aggressive is relatively small. Based upon MDS data, at a point in time, the unduplicated total number of nursing home residents exhibiting one or more behavioral symptoms was 29% (11,811 of 40,098). At a point in time only 5% of residents (2,134) displayed physically abusive behavior, the type of behavior most likely to cause harm to others, the type most applicable to this study. A smaller portion exhibited physically abusive behavior that was not easily altered: 3% (1,276). Various studies have shown that even smaller portions of these residents actually cause harm to others, but data was not available with which to assess actual harm caused by Indiana nursing home residents.

MDS data on cognitive impairment shows that, depending upon the CPS scores included, somewhere between 60%-94% of residents with physically abusive behavior are cognitively impaired, while 6%-40% are not.

Indiana State Department of Health (ISDH) data indicates that about 1,142 incidents of resident-to-resident abuse were reported by nursing facilities in a one-year period.

Notwithstanding these efforts to provide usable data, the Working Group wishes to convey its concern regarding data limitations. The Group found it difficult to document the scope of this problem because much potentially valuable data is either not collected, not reported, or is self reported, resulting in inconsistencies from staff to staff and facility-to-facility. Some researchers believe that even when behavioral incidents are reported, they are substantially underreported, for various reasons including time constraints, inadequate recognition of the importance of documenting behaviors, fear of liability, and fear of citation by surveyors. Within the broader context of elder abuse, a June 2002 Institute of Medicine (IOM) report provides information on aggression and recommends a research agenda for this and other dimensions of elder abuse. Indiana may wish to participate in more detailed studies if they are undertaken and funded by the federal government or private sources.

A variety of studies throughout the U.S. indicate that aggressive behavior is associated not only with dementia but also with depression, physical/environmental discomfort, pain, health conditions such as urinary tract infections, and histories of violent and criminal behavior.

The Working Group concluded that most aggressive behavior can be treated/minimized by facilities and their staff. Beyond medical interventions, one of the key methods is expanded use of the latest behavior management techniques.

There is a wealth of training material and trainers available on progressive behavior management techniques, however they are not used consistently or often enough. Training of staff on the front line of resident care (nurses, nurse practitioners, advanced practice nurses, nursing aides, etc.) is key because they are in the best positions to identify behavioral changes and respond. Training of attending physicians and family members also is needed.

Experts noted that guidelines/sequences/protocols have been developed for treating dementia, mental health, and co occurring disorders in the elderly with behavior management and drug therapies, but that some generalist physicians and medical directors of nursing homes are not aware of proper protocols. This can result in negative consequences for elderly patients. For example certain medications widely used to treat depression in the general population have side effects or are counterproductive for the elderly. Physicians sometimes hesitate to use medications, fearing OBRA citation for "pharmacologic restraints", even when they are needed and could be effective.

More physicians need training in proper treatment protocols, including drug treatment, for the elderly with behavior problems. Professionals in health, mental health and long-term care settings need to be trained to use proper treatment protocols, including drug protocols.

State officials should strive to ensure that appropriate medications/protocols are included on the preferred drug list under development by the Drug Utilization Review Board of Medicaid.

The Working Group concluded that in order to address demographic increases in the elderly and cognitively impaired population, more specially trained professionals are needed. More caregivers should be specially trained in geriatrics across a spectrum ranging from nurse aides (CNAs) to LPNs, RNs, nurse practitioners, advanced practice nurses, social workers, mental health practitioners, and physicians. Some Working Group members advocated more staff per patient.

Training of physicians is critical. Indiana could strive to increase the supply of geriatricians and geriatric psychiatrists in the same way that the state and IU School of Medicine promoted family practice medicine and increased the supply of family practice physicians. The School of Nursing could assist by producing more nurse practitioners and advanced practice nurses to help fill the void as well.

Human resource needs could be referred to the Governor's Commission on Caregivers for the Continuum for further consideration.

The combination of dementia and depression is fairly common and is associated with aggressive behavior among nursing facility residents, particularly when untreated. Data indicates that early assessment and treatment of behavioral, mental health and other needs is a key to preventing aggressive behavior. However, several sources indicated that the dementia exclusion in PASRR Level II pre admission screening for mental health limits the extent to which dementia patients with co occurring mental illnesses are screened and treated.

The Working Group concluded that early assessment and treatment of mental health needs, notably depression, is a key to preventing aggressive behavior. For those residents exempt from PASRR Level II, other methods should be used to assess mental illness. A range of possibilities exists, short of seeking a federal waiver of the PASRR Level II "dementia exclusion". Other than requiring the full Level II process, the state could encourage facilities, physicians, and families to refer clients for mental health needs assessments and psychiatric evaluations. Facilities should train staff to identify possible mental illness; they should be encouraged to assess, develop care plans, treat, and monitor mental health needs as required by OBRA and to contact DMHA for assistance when they cannot locate mental health providers. The Indiana Department of Mental Health could provide incentives and otherwise encourage mental health providers including CMHCs to offer comprehensive mental health screening/assessment services to nursing facilities. PASRR Level II screening is reimbursed at up to $360 per person and DMHA reports that Medicaid, Medicare, private insurance and other funding sources are usually available for non-PASRR mental health assessments when requested by the resident, facility, or the attending physician.

While lack of reimbursement options is sometimes a barrier to providing services, mental health services for the elderly can be funded by most sources….Both Medicare and Medicaid fund mental health services for the elderly.

However, DMHA reported and Working Group members confirmed that nursing homes and their trade associations are not fully aware of these Medicaid and Medicare mental health reimbursement options. Consequently, the Working Group recommends that Medicare and Medicaid reimbursement options for mental health services be publicized and marketed so that more families and facilities will take the initiative to access needed services. Consumer groups and trade associations could invite OMPP, DMHA, ISDH, and Bureau of Aging and In Home Services to provide pertinent information on this topic during periodic meetings of their members.

Even with early identification of mental health needs and Medicare/Medicaid reimbursement available for treatment, there remains a critical issue with the current and projected shortage of qualified mental health professionals, especially in rural areas.

Facilities indicate that a general shortage of mental health professionals is the underlying problem. They report that there are not enough qualified people to ensure adequate treatment and that attending physicians – often generalists in family practice and internal medicine -- may inadvertently order the wrong medications/treatment. As

indicted earlier, nursing homes generally do not offer mental health services in-house. Family members and nursing facilities must locate treatment providers on their own.

Moreover, there is a reported a lack of mental health professionals specialized in geriatric training in mental health centers and in private practice.

The Working Group supports efforts to increase the supply of mental health professionals generally and of professionals with geriatric training/cross-training specifically.

Given that Community Mental Health Centers are no longer limited to delivering services within geographic catchment areas and that some but not all have special skill in aging and geri-psychiatric services, the Working Group recommends that CMHCs interested and able to deliver specialized aging services be identified and marketed throughout the state. Further efforts and incentives may be required to encourage CMHCs to deliver services to the elderly nursing home population.

One of the keys is to bring mental health and psychiatric care on site, into long term care settings, rather than to move or transfer patients. Numerous sources indicate that movement/transfer of patients can increase agitation/aggression.

Many of the foregoing issues and solutions require the support of regulators. To minimize barriers that could inhibit use of behavior management, ISDH, consumer groups, and providers should work together to provide incentives for documentation and use of behavior management strategies. ISDH surveyors should receive ongoing training regarding behavior management strategies, appropriate medications/protocols for residents with aggressive/behavioral issue, and mental health needs and the importance of using Level I screens and MDS data to hold facilities accountable for meeting mental health needs.

Experts and Working Group members concur that the first and best treatment is behavior management by properly trained staff within the nursing facility. However, for a small subset of the total nursing home population with behavioral symptoms, something more may be needed. Indiana MDS data shows that at a point in time only 2,134 (5%) nursing home residents are physically abusive and 1,276 (3%) have behavior that is hard to change. Some of these might benefit from highly specialized care, potentially beyond the services available in a regular nursing home or special care unit.

Based on models in Northwest Indiana, New Jersey, and Minnesota, to address the very small number of residents whose behavioral symptoms are exceptionally difficult to treat in regular long term care facilities, the Working Group recommends the establishment of a few long term care facilities specialized in behavior management. Facilities should be small and have very stringent admission criteria to prevent "dumping". Facilities could be regional (for example 1 north, 1 central, 1 south) or in major population centers to ensure access for family members. Facilities should retain adequate numbers of highly specialized staff. They should also provide outreach, technical assistance and training on behavior management and medication to other facilities within their region. They should

be reimbursed at a special rate if necessary to reflect their highly specialized services and potentially higher levels of care.

Further planning is needed to address the regulatory framework for facilities specialized in behavior management, eligibility requirements, and reimbursement policies. Planning should include representatives of consumers, the health care profession, and the state (Division of Mental Health and Addiction, Department of Corrections, Division of Aging and Rehabilitative Services, Office of Medicaid Policy and Planning, Department of Health).

The FSSA Office of Medicaid Policy and Planning reported to the Working Group on a detailed time study conducted in Indiana to assess the adequacy of Medicaid reimbursement for nursing home residents with Alzheimer's and related dementias, in both regular and special care units. It found that RUG reimbursement does not seem to fully reflect resource use on Alzheimer's unit residents. Even after taking ADL differences into account, many Alzheimer's unit residents received more direct care (particularly unlicensed staff time) than either cognitively impaired or non-cognitively impaired residents on regular units.

Consequently, the Working Group recommends that findings from the FSSA Office of Medicaid Policy and Planning time study on reimbursement of dementia care in Indiana special care units in Indiana be addressed once budget and further information needs are met. The group concurs that it will be necessary to define/regulate what makes special care units special prior to reimbursing them at a higher level.

In addition, the Working Group recommends that FSSA OMPP consider a similar study for residents with behavior symptoms, with and without cognitive impairments. Other studies imply that dealing with difficult behaviors may require additional staff time regardless whether residents are cognitively impaired.

Finally, the Working Group recommends further study of legal/justice system issues surrounding elder abuse and the aging of people with violent and/or criminal histories. Adult Protective Services agents had a 150% increase in reported cases of elder abuse nationwide from 1986 to 1996. Moreover while the Working Group focused on aggressive behavior among nursing home residents with dementia, comparable attention could be placed on residents with violent/criminal histories. While justice system issues and solutions were beyond the scope of this study, it became apparent that dementia/cognitive impairment does not fully explain behavioral issues in nursing homes. Cases, such as the one in Evansville, can be traced to people with histories of violence as well as cognitive impairment.

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Appendices

1 – Article About Evansville Case of Barbara Becker

2 – Senate Concurrent Resolution 18

3 – Summary of Indiana Ombudsmen Focus Group April 10, 2002

4 – Data from Indiana State Department of Health

5 – Excerpts from Oregon Study of Aggressive Behavior Among Nursing Facility Residents

6 – Indiana Pre Admission Screening Forms

7 – New Jersey regulations for specialized regional behavior management units

Appendix 3

Summary of Indiana Ombudsmen Focus Group April 10, 2002

Problems/Issues/Observations about Aggressive Behavior

Triggers: invading resident space; residents can't find their room

Triggers: malnutrition and dehydration; lack of activity

Triggers: didn't want to be in locked ward; residents in early stage are unwilling to accept late stage

1/3 to 1/2 of all ombudsmen calls are from facilities with behavior problems they don't know how to solve

Nursing homes try to make residents fit their routine instead of the reserve

Residents are transferred or discharged, informally or informally, to psych wards then not readmitted

Alzheimer's is not in DSM 4 so you can't get professional mental health services and/or providers are not well versed in proper use of drug therapies

It's not just for Alzheimer's…our mental health center refuses to serve nursing homes generally. They say they don't do dementia; this may be a reimbursement issue; with mental health hospital closings, some residents have moved to nursing homes

Special care units have become catch-alls for MRDD, all dementias

If surveyors are coming, problem residents are removed;

Psychiatric units won't take residents back due to reimbursement issues and nursing homes do not want to readmit, therefore there is no continuity of care

Only a small subset cannot be treated/managed – There are no facilities for these, no reimbursement

Some long term care corporations have more problems than others; may be rooted in home office/not enough training and follow through

Prior to survey, residents are transferred

ISDH pressures facilities to move residents to "get rid of the problem" instead of solving the problem; they often end up in facilities with lots of vacancies, i.e. less desirable facilities, where they are "dumped"

Some facilities claim to have special care units with staff trained in aggressive behavior but still get residents who can't be redirected, then have hard time working with mental health system to solve

Some residents of group homes are moved to nursing homes due to illness/injury, then can't get back into group home; must go onto waiting list

Aging in place; as the mental health institutional population ages, they are placed in nursing homes; they get mental health follow up for only 30 days (similar is true for correctional population)

Solutions/Resources

Need more staff training, including prevention of behaviors

Need more behavior tracking pre and post admission to determine life long patterns

Need specialized special care units

Need to develop cooperation among systems for aging, mental health, and developmentally disabled

Appendix 4
Data from Indiana State Department of Health

From ISDH surveyor reports on compliance with state and federal regulations in calendar year 2001 (1-1-01 to 12-31-01), ISDH recorded 214 deficiencies/tags (rule violations) for regulation F324, which according to ISDH includes but is not limited to resident-to-resident abuse. F324 states "Quality of Care. Each resident receives adequate supervision and assistance devices to prevent accidents."

Deficiencies/tags/rule violations are classified A – L, with A being the lowest risk (isolated incidents with no actual harm with potential for minimal harm) and L being the highest risk (widespread incidents with immediate jeopardy to resident health or safety). The 214 tags for F324, were distributed as follows:

Tags for F324	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
Certification survey				15	36	4	54	5		2	4	
Post certif. review follow up on site	1			2	4		8	1		4		
Multiple PCR follow up on site							5			2	1	
Complaint investigation				6	5		34	4		2	5	
Follow up on complaint investigation				1	3		6					
Total 214	**1**	**0**	**0**	**24**	**48**	**4**	**107**	**10**	**0**	**10**	**10**	**0**

From ISDH surveyor reports, ISDH recorded **21 deficiencies or tags for regulation F223** regarding abuse as follow. F223 states "Abuse. The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion."

Tags for F223	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
Certification survey							3	1			1	
Post certif. review follow up on site				1	1							
Multiple PCR follow up on site												
Complaint investigation				1			6	3			1	1
Follow up on complaint investigation					1						1	

Total 21	**0**	**0**	**0**	**2**	**2**	**0**	**9**	**4**	**0**	**0**	**3**	**1**

ISDH completed a word search to locate the word "Alzheimer's" in its records of all deficiencies/tags (n=4,419). This search revealed 55 types of deficiencies, with a total of 253 deficiencies involving residents with Alzheimer's disease in some way. The most frequently occurring deficiency was F324 (n=62). Details follow.

Tags including the word "Alzheimer's"	**F223**	**F324**	**Total # Tags including the word Alzheimer's**
Certification survey	0	22	166
Initial certification survey	0	0	3
PCR follow up on site	0	3	16
Multiple PCR follow up on site	0	3	6
Complaint investigation	1	17	50
Follow up on complaint investigation	1	12	12
Total	2	62	253

Appendix 5
Excerpts from Oregon Study of Aggressive Behavior Among Nursing Facility Residents

A detailed study of physically aggressive behavior among **Oregon nursing facility residents** (Asmann, Singer and Moreland) used MDS data on physically aggressive behavior, a survey of facilities, and anecdotal information to generate the following findings:

Oregon has an extensive community based care program, so comparatively few people live in nursing homes…The individuals who reside in Oregon's long term nursing facilities are the most cognitively impaired individuals in the state…physically aggressive behavior is often a symptom of dementia. The percent of the population that acquires dementia increases with age. As the population of the United States ages, increasing numbers of seniors, who require long-term care, will have dementia. Therefore, the number of these persons who display physically aggressive behavior will increase and the rate of increase will grow as the population ages.

The study included a total sample of 301 residents, 201 in a physically aggressive behavior (PAB) group and 99 in a control group.

- **5.56% of nursing facility residents** exhibited physically aggressive behavior according to the MDS but only 77% of these were documented in clinical records as having caused harm to others, for an adjusted physically abusive rate of **4.28**%. A written survey of Oregon nursing homes indicated that **5.83**% of all residents displayed aggressive behavior. *(Similarly, Indiana's MDS data revealed 6% with physically abusive behavior.)*
- **Men** had greater representation in the physically aggressive group (9% more) than in the control group
- The study examined the medical records for documentation of diagnoses of dementia, major mental illness, urinary tract infection, pain, and other diagnoses. The **rate of dementia (non-Alzheimer's type**) in the physically aggressive group (71.1%) was significantly higher than in the control group (51.1%)
- Physically aggressive residents are more likely than the control group to be referred for **mental health services**, but the percent is low. Fourteen percent of the PAB group was referred for mental health services compared to 3% of the control group.
- 30% of the PAB group had received mental health services compared to 9% of the control group. Thus, 70% of people with physically aggressive behavior had not received mental health services.
- **Only 7.7% of all study subjects received at any time a mental health assessment under the Pre Admission Screening Resident Review (PASRR) program**. Although some residents from the control group (2%) and the PAB group (5.7%) received a PASRR assessment, almost none of those received other mental health services (.33% of the control group and 2% of the PAB group).
- The **largest difference between groups is in the use of antipsychotic medication.** Forty three percent of the PAB group was taking antipsychotic medications, compared to 21% of the control group. The control group used a little more antidepressant than the PAB group (51.5% vs. 43.3%). The PAB group took more anti-anxiety medication than the control group (23.4% vs. 17.2%).
- Of all types of physically aggressive behavior, **resisting care and hitting/squeezing were the most frequent behaviors** reported. Resisting care occurred in 10.1% of the control group and 43.8% of the PAB group. Hitting/squeezing occurred in 11.1% of the control group and 38.3% of the PAB group.
- There was a marked difference between the control group and the PAB group regarding **severity of outcome to others**. The physically aggressive behaviors displayed by the PAB group were over **four times more severe** than the control group.
- **22% of the PAB group** displayed aggressive behavior that **resulted in actual harm to others**
- **Extrapolating this to Oregon's whole nursing home population, from .6% to 1.08% of nursing facility residents engage in behavior that causes harm to others.**
- Overall **80% of incidents of physically aggressive behavior are directed toward staff** (90% for the control group and 83% for the PAB group). The PAB

group had nearly twice the proportion of physically aggressive behavior toward other residents (17%) compared to the control group (10%).

- Residents with physically aggressive behavior resulting in harm to others **are different** from residents who do not display these behaviors.
    - **Care planning for pain** appears to have relevance to the seriousness of physically aggressive behavior…the number of residents with pain increased with the severity of outcome.
    - **Alzheimer's Disease** appears to contribute to physically aggressive behavior.
- Anecdotally, some staff report that they become familiar with a resident's routinely aggressive behavior and **only document the most serious incidents.** Observational study would clarify whether or not staffs accurately document incidents of physically aggressive behavior.
- Nursing notes described incidents where **one resident provoked another resident to violence**; the notes frequently described the provoking resident as the aggressor rather than the resident who actually initiated the violence.
- There is little difference between the groups regarding diagnoses, except in the case of non-Alzheimer's dementia where 19.6% more PAB group residents had dementia and 4.9% more PAB group residents had brain injury.
- **Alzheimer's Disease emerges as a significant factor when harm groups are compared. Those residents who display the most serious and greatest variety of physically aggressive behavior all have dementia,** while some of the residents who display milder forms of physically aggressive behavior do not. The severity of dementia, including Alzheimer's disease, or how well the symptoms of dementia are managed may be key factors that determine the severity of behavior.
- Residents who cause harm to others have the following traits:
    - Alzheimer's Disease or another dementia
    - Care plan for pain
    - Are prescribed analgesics which are not given and
    - Use anti-psychotics
- **Pre-existing psychological disorders or personality traits were not assessed in this study.** But anecdotal information from staff suggests that these may be significant contributors. Residents who have borderline personality disorder or have a life-long history of aggressive behavior may be inclined to display physically aggressive behavior if they also have dementia.
- **Nursing facilities are not making significant use of mental health resources outside of medication**. One would expect that facilities would refer a majority of physically aggressive residents for a PASRR (mental health) evaluation and access mental health resources for these residents. But, only 4% to 7% are referred for a PASRR and 70% have received no mental health services.